

We need to talk about Palliative Care

Royal College of Nursing Scotland

Additional written statement by Sandra Campbell, Macmillan Nurse Consultant for Cancer and Palliative Care, NHS Forth Valley and witness for RCN Scotland.

There was some discussion by witnesses around how we can raise public awareness of palliative care and make that cultural shift to get people to talk more openly about the care that they wish to receive.

From my experience, palliative care is about adopting a comfort approach for the patient which may be required many years before they are actually at the end of their life. In that context it is crucial that people are able to talk more freely about the kind of care that they wish to receive and that their family and carers are a part of that process. It is also crucial that the care is available at that stage. High quality palliative care can help patients and their families to deal with the practical and emotional side of their condition and can help to ensure that the end of life is as peaceful as possible.

The difficulty when someone has palliative care needs for a long period of time is identifying the decline. This was an issue which a number of witnesses raised and I would echo much of what was said in relation to the variety of definitions in use clouding action in some cases. If I recall, witnesses in the first panel were asked whether is definition issue was a barrier to accessing palliative care. I would agree with much of what Dr David Carroll said on this point:

“Palliative illnesses are ongoing illnesses. There is a continuum from the point of diagnosis ultimately through to death. There will be decline, and there will be fading timescales. What the person and their family require is appropriate care at specific points throughout the illness.”

I would add that nurses do provide most of the care at the end of life, but that a joined up approach in providing that care is essential. It is beneficial for patients and crucially it helps to support families at what is a very difficult and often traumatic time. District nurses should lead the delivery of end of life care in the community. A clear lead can ensure that services are as joined up as possible and that there is as much continuity of care and support as possible.

Within that end of life care, the dying phase is highly significant. It is vital that care is coordinated, and again provided by health teams with a clear lead, to ensure that patients get the care that they need. This approach is also valuable in making sure that families are informed about the care that their loved one is receiving and that they are supported through the death. Essentially, the health team lead approach ensures consistency of care by those who are familiar to both the patient and their support network.

There was a lot of discussion throughout the evidence gathering process which centred on end of life care at home or in a hospice setting. I do,

however, feel it is crucial that there are options available to people for whom dying at home is not their preferred option. There is therefore a real need for community based facilities, such as community hospitals, which are equipped to provide high quality end of life care. And it is imperative that there is direct access to these care settings to ensure that the medical intervention approach of acute medicine is avoided.

Part of ensuring that there is direct access to such care settings is to ensure that there is excellent quality advice and support for palliative care patients out of hours. This point is true for palliative patients no matter what stage of their illness they are at. Palliative specialists being available to offer advice and support out of hours is crucial not only to ensuring the highest quality care but also to identifying a patient's decline which, as many witnesses said, is crucial. It also would ensure equality of service provision which I know was a concern to the committee.

The final point I would wish to make is that whenever we are talking about care teams it is essential that social work care teams and the third sector are involved. The NHS cannot provide all of the care and support that palliative patients and their families need. It is crucial that patients and families do have this support and that means that we must acknowledge the huge role that social care professionals and the third sector provide.

If we are to ensure that every patient gets the care that they should, whether through a palliative illness or at the very end of their life, I do believe that these points need to be considered and acted upon. The majority of care in Scotland is very good, but everyone must have access to it.

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